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Development of health-related quality of life and symptoms in patients with advanced cancer in Greenland

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A prospective national cohort study assessed the development of health-related quality of life (HRQoL) and symptoms in adult patients undergoing treatment and care for advanced cancer in Greenland. HRQoL was examined by EORTC QLQ-C30 version 3.0 questionnaire monthly for 4 months. Changes over time and between-group comparisons were examined. Of 58 patients included in the study, 47% completed the questionnaire four times. Functioning was generally high, and improved social functioning was observed after 1 and 2 months. The highest symptom score was for fatigue followed by pain and nausea/vomiting. A high score for financial problems remained unchanged during the entire period. Patients with higher income had reduced pain intensity ($p = .03$) and diarrhoea ($p = .05$) than patients with income below the poverty line. After 1 month, reduction in pain intensity was observed for Nuuk citizens compared with non-Nuuk citizens ($p = .05$). After 2 months, non-Nuuk citizens reported improved social functioning compared with Nuuk citizens ($p = .05$). After 3 months, Global Health in Nuuk citizens was improved compared with non-Nuuk citizens ($p = .05$). An important clinical finding was that patients' needs for support are related to social status, and geographical factors should be taken into account when planning palliative care.

KEYWORDS

health-related quality of life, palliative care, prospective study, remote areas, symptom management

1 | INTRODUCTION

Remote areas like Greenland face unique challenges in ensuring availability and accessibility of healthcare services (Pong & Pitblado, 2002; Sibley & Weiner, 2011; Wilson & Rosenberg, 2002), and delivery of palliative cancer care is no exception (Wilson et al., 2006). Greenland has a total area of over 2 million km², and about 80% of the island is covered by permanent ice. The population is about 56,000 and lives scattered along the coastline. Most are Inuit, and only 10%

have been born outside of Greenland (Statistics Greenland, 2016). In 2013, 105 patients died of cancer, which is a leading cause of death in Greenland (The National Board of Health G, 2014). Cancer incidence in 2012 was 164, with a rate of 289 per 100,000 inhabitants (The National Board of Health, 2013). The Greenlandic lifestyle has been changing rapidly, and the increasing incidence of cancer appears to be related to demographic, geographic, socio-economic and environmental factors (Petersen & Bjerregaard, 2014). Indigenous people in the Arctic region have increasing incidence of cancer, and

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their risk is higher than the world average for lung or colorectal cancer (Young, Kelly, Friberg, Soininen, & Wong, 2016).

Greenland is part of the Danish Realm, and antineoplastic treatment is provided in close collaboration with Danish hospitals. As of 2004, chemotherapy for breast, lung, pancreatic and gastrointestinal cancer was treated in collaboration with oncologists at Rigshospitalet and is administered at Queen Ingrid's Hospital (QIH) in Nuuk (Gelvan, Risum, & Langer, 2015). Patients living outside Nuuk usually have to travel long distances for antineoplastic treatment and may be separated from their families for long periods, which may reduce their quality of life. In addition, patients and their families in remote areas can have a wide range of unmet needs including access to services, information, practical help and medical support (White et al., 2011).

Specialist palliative care is not yet available in Greenland but is being planned, and knowledge about the needs of patients with advanced cancer and their relatives is of high priority (Departementet for Sundhed D, 2015). Studies on illness development and health-related quality of life (HRQoL) are important to identify current needs and to promote a clinical and research agenda in Greenland. Furthermore, assessment of symptoms and health-related quality of life is useful in measuring the effectiveness of future interventions for patients with advanced cancer (Lavergne, Johnston, Gao, Dummer, & Rheume, 2011; Reeve et al., 2013).

Structured use of assessment tools aims at providing symptom relief, but can also enhance research, education and public awareness of palliative care (Strömberg, Goldschmidt, et al., 2002). The Greenlandic version of the EORTC QLQ-C30 has recently been translated and partly validated in a cross-sectional study. The Greenlandic version of the EORTC QLQ-C30 proved to be an applicable and reliable tool. The study demonstrated that patients with advanced cancer reported high levels of social and financial problems and reduced physical functioning. The study indicated a potential for establishing palliative care service in Greenland (Augustussen, Sjøgren, Timm, Hounsgaard, & Pedersen, 2017).

The aim of this prospective study was to assess the development of symptoms and HRQoL in patients with advanced cancer in Greenland.

2 | METHODS

2.1 | Study design and recruitment of participants

From June 2015 to March 2016, a prospective observational study was undertaken in a population of patients with advanced cancer in Greenland.

Recruitment of patients was based on the electronic medical records (EMR) by extracting cancer diagnoses according to ICD-10 DC00-DD48 codes. The EMR for patients with a registered cancer diagnosis, who had been in contact with the healthcare system, was assessed to identify eligible patients with advanced cancer.

All eligible patients were contacted by telephone and provided with information about the purpose of the study. Patients were included consecutively during the observation period of 4 months.

2.2 | Inclusion and exclusion criteria

Inclusion criteria were patients aged 18 years and over, with permanent address in Greenland and in treatment for advanced cancer disease with non-curative or no antineoplastic treatment options. Exclusion criteria were information in the EMR about cognitive impairment or inability to answer questionnaires.

2.3 | Setting and data collection

The healthcare system is organised in five healthcare regions, with QIH in Nuuk functioning as the central hospital. Chemotherapy is given according to Danish guidelines in an outpatient clinic in the department of internal medicine at QIH (Gelvan et al., 2015). Patients from other villages and settlements are transferred for treatment by helicopter, boat, plane or ship. Healthcare services including medication, hospital treatment and transportation to hospital are free of costs for permanent inhabitants in Greenland. Some patients receive oncological treatment at a Danish hospital after assessment and referral from a physician.

Data collection was primarily through structured telephone interviews, supplemented with face-to-face interviews in Nuuk if patients were available and/or preferred this contact form. Each patient completed the EORTC QLQ-C30 questionnaire at baseline and then once a month for 4 months.

2.4 | Assessment

HRQoL refers to different aspects of quality of life (physical, emotional, social and role functioning and general well-being), and the EORTC questionnaires have been translated and validated in over 100 languages worldwide and used in more than 3,000 studies (European Organisation for Research and Treatment of cancer webpage). The EORTC QLQ-C30 core version 3.0 is a cancer-specific and multidimensional questionnaire designed to explore different aspects of functionality, symptomatology and HRQoL (Wintner et al., 2016). The Greenlandic version was recently validated and showed acceptable internal consistency in the assessment of symptoms and HRQoL among Greenlandic patients with advanced cancer (Augustussen et al., 2017). The validated Danish version of the EORTC QLQ-C30 was completed by Danish-speaking patients (Strömberg, Groenvold, Pedersen, Olsen, & Sjøgren, 2002).

The EORTC QLQ-C30 consists of five function scales (physical, role, cognitive, emotional and social), three symptom scales (fatigue, pain and nausea/vomiting), a global health status scale and six single items (dyspnoea, loss of appetite, insomnia, constipation, diarrhoea and financial problems). According to the scoring manual, each item score is transformed into a 0–100 scale (Fayers et al., 2001). Scoring on the single items is thus 0 (Not at all), 33.3 (A little), 66.7 (Quite a bit) and 100 (Very much). Higher scores on the functioning scale reflect better functioning, while higher scores on the symptom scales and

single items reflect a high level of symptoms (Fayers & Bottomley, 2002).

Inspired by King (1996) we considered a difference in scores of 10 clinically significant for the EORTC QLQ-C30 scales.

Although no official definition of poverty exists in Greenland, patients with self-reported annual income below 14,805 US dollars were categorised as poor, in line with the official Danish poverty line (Schnohr, Nielsen, & Wulff, 2007).

2.5 | Statistics

Variables were dichotomised in the statistical analysis and described using means and standard deviation (SD). Mean differences in scores were calculated by subtracting scores from baseline (T1-T0, T2-T0 and T3-T0). Comparisons between groups (lung cancer vs. non-lung cancer, lower income vs. higher income, Nuuk citizens vs. non-Nuuk citizens) were made using Wilcoxon's rank test. A *p*-value below .05 was used as level of significance. SAS version 9.4 was used for all statistical calculations.

2.6 | Ethics

The project was assessed according to the Helsinki declaration and was approved by the Ethics Committee for Medical Research in Greenland (2014-102760) and the Data Protection Agency in Denmark (2014-41-3660). Permission to review data from the EMR was given by data owner Agency of Health and Prevention in Greenland. Informed consent was obtained after giving all participants a thorough written and oral presentation of the study. They were informed that participation was voluntary and that they could withdraw from the study at any time without consequences for their treatment and care.

3 | RESULTS

3.1 | Participants

A total of 664 patients with a cancer diagnosis were identified through the EMR system. During the inclusion period from June 2015 to March 2016, 82 patients were found eligible. Six of them died before contact, nine declined to participate, and nine did not respond to phone calls. Reasons for declining were that patients did not have time and/or energy to participate.

Figure 1 illustrates participating patients and dropouts. In total, 58 patients completed the questionnaire at baseline and were included in the study, giving a response rate of 71% (58/82).

Of the 58 patients, 27 (47%) completed the full observation period, 12 patients died, 16 dropped out and three were excluded (Figure 1). Reasons for dropping out were that patients did not have time and/or energy. The reasons for exclusion in three patients were that palliative care shifted to curative intentional treatment or cognitively impairment.

Patients' characteristics at baseline are shown in Table 1. Mean age for men was significantly higher (62 years) than for women

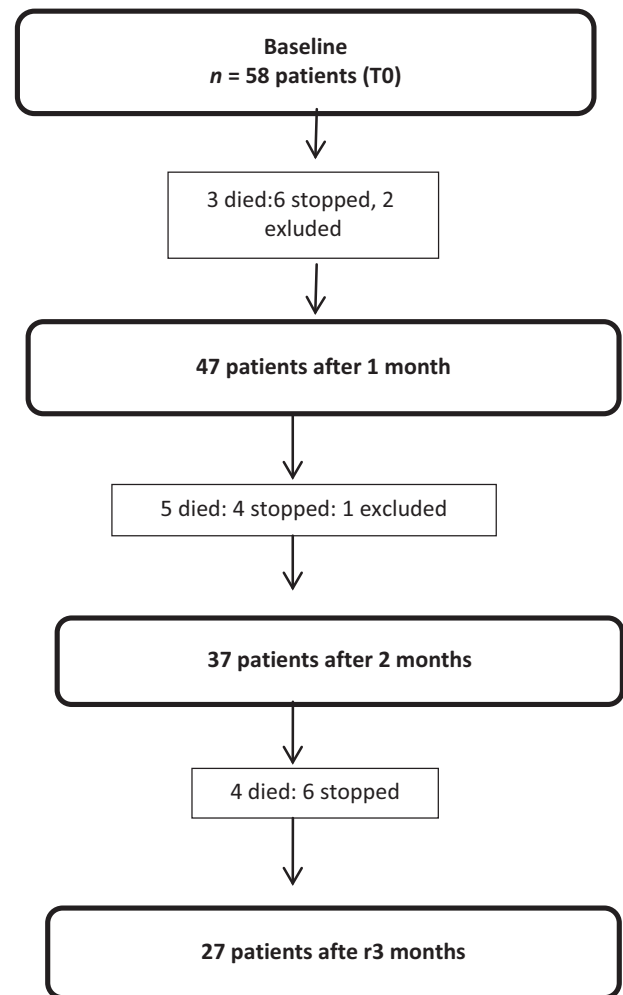


FIGURE 1 Flow diagram illustrating participating patients and dropout

(56 years; *p* = .013), one-third of patients had elementary school as highest education, and half of the patients had an income below the Danish poverty line. Lung cancer (45%) was the most common cancer diagnosis.

3.2 | Functional and symptom scores

A general overview of mean scores, regardless of characteristics, for the four observation points is provided in Table 2. All functional scores were generally high throughout the observation period. The highest symptom score was noted for fatigue, followed by pain and financial problems.

Table 3 shows changes in mean scores at four observation points and the statistically significant differences. Statistically significant improvement in social functioning was seen after 1 month (*p* = .009) and 2 months (*p* = .0012) respectively. A statistically significant decline in Global Health was observed at 1 month, although the clinical relevance appeared to be marginal due to a reduction of 8 in the mean score (*p* = .009).

Characteristics	All N = 58	Male N = 37	Female N = 21
Mean age (SD)	59	62 (9)	56 (8)
Single living, n (%)	23 (39)	13 (35)	10 (47)
Lung cancer, n (%)	26 (45)	20 (54)	6 (29)
Low income < 14.980 USD	30 (51)	17 (46)	13 (62)
Nuuk resident, n (%)	14 (24)	7 (19)	7 (33)
No education/elementary school, n (%)	20 (34)	10 (27)	10 (47)

TABLE 1 Basic characteristics of participants with advanced cancer

TABLE 2 Overview of mean scores from baseline to the third month

	Baseline mean (SD) n = 58	After 1 month (SD) n = 47	After 2 months (SD) n = 37	After 3 months (SD) n = 27
Functional scales				
Physical functioning	69 (22)	64 (24)	63 (24)	62 (23)
Role functioning	63 (31)	53 (31)	59 (32)	50 (32)
Emotional functioning	77 (21)	76 (23)	79 (24)	81 (17)
Cognitive functioning	76 (24)	81 (22)	75 (24)	72 (28)
Social functioning	55 (35)	66 (31)	68 (29)	62 (37)
Global health status/QoL	66 (23)	59 (23)	70 (22)	61 (24)
Symptom scales				
Fatigue	39 (27)	41 (27)	37 (32)	44 (29)
Nausea/vomiting	11 (15)	17 (27)	14 (18)	18 (25)
Pain	31 (27)	28 (32)	36 (38)	37 (34)
Single items				
Dyspnoea	25 (33)	32 (36)	29 (30)	39 (39)
Insomnia	28 (31)	30 (34)	27 (36)	28 (34)
Appetite loss	24 (31)	24 (29)	27 (38)	38 (40)
Constipation	21 (32)	25 (32)	21 (36)	32 (36)
Diarrhoea	19 (28)	15 (25)	15 (25)	13 (23)
Financial problems	33 (41)	37 (41)	35 (40)	33 (45)

3.3 | The impact of cohabitating status, income, diagnosis and residence

Cohabiting patients reported significantly more insomnia than did patients living alone at 2 months ($p = .04$) and 3 months ($p = .01$). Furthermore, emotional functioning at 3 months for patients living alone had improved significantly more than for cohabitating patients ($p = .04$).

At 3 months, patients with higher income had significantly reduced pain intensity ($p = .03$) and diarrhoea ($p = .05$) than patients with income under the poverty line.

Compared to non-lung cancer patients, those with lung cancer had significant improvement in social functioning at 2 months ($p = .0015$).

At 1 month, significant reduction in pain intensity was observed for Nuuk citizens compared with non-Nuuk citizens ($p = .05$). At 2 months, non-Nuuk citizens reported significantly improved social functioning compared with Nuuk citizens ($p = .05$). At 3 months,

Global Health in Nuuk citizens was improved compared with that of non-Nuuk citizens ($p = .05$).

4 | DISCUSSION

This prospective longitudinal study took place in a unique geographical environment, where palliative care in both the main hospital and the community (primary and secondary palliative care) is at a basic level, and specialised palliative care is not yet established. It is one of the first studies to assess the physical, emotional, social and cognitive problems in patients with advanced cancer in Greenland (Augustussen et al., 2017). Assessment of symptoms in Greenlandic patients with advanced cancer will hopefully not only provide a basis for future planning, but also enhance the focus of healthcare professionals working in the Greenlandic healthcare system on the benefits of systematic assessment (Homsí et al., 2006). The current study was based on consecutive patients referred to QIH and, although

TABLE 3 Changes in mean scores for all patients from baseline to T1, T2 and T3

	Change T1-T0	p-value	Change T2-T0	p-value	Change T3-T0	p-value
Physical functioning	-4	.4404	-5	.3444	-4	.3014
Role functioning	-7	.0866	2	.7968	-2	.8944
Emotional functioning	0	.7287	3	.8032	5	.1863
Cognitive functioning	2	.5239	-2	.8133	-5	.5523
Social functioning	10	.009*	13	.0012*	9	.1001
Global health status/ QoL	-8	.009*	3	.3734	-6	.1989
Fatigue	4	.1065	1	.8754	8	.1806
Nausea/vomiting	6	.1048	3	.3929	8	.1191
Pain	-4	.3954	5	.1910	3	.7008
Dyspnoea	5	.3364	0	.9496	5	.6773
Insomnia	-1	.9506	-2	.7917	-1	1
Appetite loss	1	.8539	5	.3879	12	.0979
Constipation	4	.3232	1	.7693	10	.2676
Diarrhoea	3	.4366	2	.6914	0	1
Financial problems	3	.7328	0	.9608	-6	.5664

Statistically significant p-value marked with*.

the sample size is small, it represents the first attempt to assess the developments HRQoL and symptoms in a Greenlandic population of patients with advanced cancer.

Compared to Danish patients with advanced cancer in specialised palliative care, the Greenlandic patients had higher scores on all functional scales throughout the period (Strömberg et al., 2005). The mean scores at baseline for the Danish palliative population were as follows: physical 30, role 14.5, emotional 55.9, cognitive 50.7 and social 46.6, whereas the corresponding figures for Greenlandic population were 69, 63, 77, 76 and 55 for social functioning. Thus, the functional scores in patients with advanced cancer in Greenland are considerably higher, which may involve selection of patients during the disease trajectory in Denmark and Greenland due to different living conditions and healthcare systems. Regarding the latter especially availability and accessibility of treatment and care, which for the Greenlanders may involve long travel distances—particularly, for those residents outside Nuuk. Although the Danish study is now 12 years old, these findings are extremely interesting and worthwhile investigating more details in future studies.

The most striking finding was that financial problems, which may be associated with the lower scores on social functioning, persisted throughout the study period, indicating that most patients had economic difficulties. The observed differences between Greenlandic and Danish patients may be partly explained by pronounced income differences between the two countries. The average personal income in Greenland is 32.948 USD (Statistics Greenland, 2016) while that in Denmark is 45.089 USD (Danmarks Statistik, 2016). Further, a recent survey showed that inhabitants of settlements and smaller cities were less educated than those living in Nuuk and were more likely to supplement their income with hunting and fishing (Petersen

& Bjerregaard, 2014). This supplement may be harder to achieve when a family member has advanced cancer and has to travel to treatment every 3 weeks. Fatigue was the most frequently reported symptom followed by pain, as demonstrated in other prospective studies (Färkkilä et al., 2014; Homsí et al., 2006; Strömberg et al., 2006).

As expected, patient attrition was high, and only 47% of patients completed the 4-month study period. Previous longitudinal studies in patients with advanced cancer have reported substantial problems due to attrition (Strömberg et al., 2005). In our study, 11 patients dropped out at the start and then approximately 10 per month in the rest of the observation period. The main reasons for dropping out were insufficient time or energy. Some patients felt that the questionnaire completion was too time-consuming for them and that it had no impact on clinical practice.

Previous studies in similar populations have shown that patients not participating in a study were more frail, older and had shorter survival than participants (Ahlner-Elmqvist, Bjordal, Jordhøy, Kaasa, & Jannert, 2009; Strömberg, Goldschmidt et al., 2002). It was concluded that non-participants had more advanced-stage disease and more pronounced symptomatology. Thus, the current study may have some selection bias resulting in underestimation of symptomatology and overestimation of functional capacity and HRQoL.

The small sample size (reflecting the small number of patients with advanced cancer in Greenland) limited statistical analysis, especially regarding predictor and subgroup analysis that could have contributed with more information for major subgroups of patients. With these precautions in mind, between-group comparisons can still illustrate possible trends, however. We found that patients living alone achieved better social functioning and relief of insomnia than

cohabitating patients. A Danish study similarly found that patients living alone achieved more symptom relief than did cohabitating patients (Strömgen et al., 2005). However, in a Greenlandic setting, our findings may be explained by the patients living alone receiving more public assistance and attention, as the assessment of needs for assistance is mainly based on social living situation (The Government of Greenland, 2006).

In a healthcare system with limited resources, a part of the everyday life is to prioritise between the patients who are referred. The capacity of specialised palliative care in Denmark is substantially lower than that recommended by the EAPC (Radbruch & Payne, 2009), and as mentioned earlier specialised palliative care is not available in Greenland. The late introduction of palliative care and the low public awareness of palliative care in Denmark may have affected the situation in Greenland (Hoeftler & Vejlgård, 2011). The finding that higher-income patients had significant reduction in pain intensity and diarrhoea compared with patients under the poverty line may be indirectly due to well-known inequality of access to health care associated with socio-economic factors (Dixit, Crawford, Lemonde, Rittenberg, & Ortega, 2016). The relatively limited access and availability of health care in general, and palliative care in particular, may have important consequences for certain subgroups, for example individuals with lower income.

Our observation that lung cancer patients showed significant improvement in social functioning during the observation period compared with non-lung cancer patients is not readily explainable. It is possibly due to greater focus from the healthcare system on this major diagnosis, which is often associated with poor prognosis, a heavy symptom burden and emotional distress (Morrison et al., 2017).

Finally, we found that during the observation period non-Nuuk residents reported worse pain and HRQoL than Nuuk citizens, which might be explained by limited access to QIH and/or the strenuous travelling for treatments and separation from relatives. At 2 months, however, non-Nuuk citizens had improved social functioning compared with Nuuk citizens.

Provision of palliative care in remote areas faces geographical and logistic challenges (Dewar et al., 2003; Duggleby et al., 2011; White et al., 2011). Healthcare services in Greenland provide primary care (delivered by generalists such as general practitioners, family physicians and general internists) and secondary care (by oncologists) for the treatment of cancer, but not tertiary palliative care (by specialist palliative care physicians). This approach is based on the concept that most palliative care can (and should) be provided by generalists, with oncologists managing specific issues, and palliative care specialists providing consultation for complex problems (Ferris et al., 2009). Thus, educational initiatives and a higher degree of integration between primary and secondary levels may be a way to strengthen palliative care in Greenland. According to the EAPC white paper, however, a palliative care specialist team situated at QIH could be justified on the basis of Greenland's population size (Radbruch & Payne, 2009). The geographical challenges mean that telehealth services could be appropriate to provide cancer care in remote places,

as described in several studies conducted in rural and remote areas (Donnem et al., 2012; Hebert, 2007; Laila, Rialle, Nicolas, Duguay, & Franco, 2008). Finally, clinical implementation of systematic symptom management seems to be highly warranted in the Greenlandic population of patients with advanced cancer (Augustussen et al., 2017).

5 | CONCLUSION

This prospective observational study shows improvement on social functioning and decline in Global Health in patients with advanced cancer. An important clinical finding is that patients' needs for support are related to social income, and geographical factors should be taken into account in symptom management. High economic problems were reported during the entire period. Even though all patients needed support and symptom management, it is noteworthy that non-Nuuk resident seemed to have heavier symptom burden. This is an important clinical finding and shows that patients' needs for support are related to social income and attention is needed on geographical factors.

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